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Research Article

Promoting and Protecting Against Stigma in Assisted Living and Nursing Homes

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Abstract

Purpose of the Study: To determine the extent to which structures and processes of care in multilevel settings (independent living, assisted living, and nursing homes) result in stigma in assisted living and nursing homes.
Design and Methods: Ethnographic in-depth interviews were conducted in 5 multilevel settings with 256 residents, families, and staff members. Qualitative analyses identified the themes that resulted when examining text describing either structures of care or processes of care in relation to 7 codes associated with stigma.
Results: Four themes related to structures of care and stigma were identified, including the physical environment, case mix, staff training, and multilevel settings; five themes related to processes of care and stigma, including dining, independence, respect, privacy, and care provision. For each theme, examples were identified illustrating how structures and processes of care can potentially promote or protect against stigma.
Implications: In no instance were examples or themes identified that suggested the staff intentionally promoted stigma; on the other hand, there was indication that some structures and processes were intentionally in place to protect against stigma. Perhaps the most important theme is the stigma related to multilevel settings, as it has the potential to reduce individuals' likelihood to seek and accept necessary care. Results suggest specific recommendations to modify care and reduce stigma.

Keywords: Structures, Processes, Outcomes, Multilevel settings, Continuing care retirement community

Forty years ago, the U.S. Senate Special Committee on Aging proclaimed there to be a failure of nursing home (NH) care; the committee referred to the "dread and despair" of NHs that were "repositories of the unwanted," attributing responsibility to public policies combined with ageist attitudes (Subcommittee on Long-Term Care, 1974, pp. iii, 160). Fortunately, NHs and other long-term services and supports have evolved since that time. NH care has moved to become more person centered in response to "culture change" efforts and related policies (Zimmerman, Shier, & Saliba, 2014), and assisted living (AL), which is expressly meant to promote dignity and respect (Assisted

Living Quality Coalition, 1998), burgeoned into a residential supportive care industry caring for almost 750,000 older adults in 31,100 residences across the country (Park-Lee et al., 2011). However, despite this evolution, there is no evidence that the stigma associated with residence in NHs has lessened, and in fact, there is evidence that AL harbors ageism and stigma related to residents' cognitive and physical impairment (Dobbs et al., 2008).

Harboring negative attitudes toward the receipt of care or residence in a supportive environment—whether or not such attitudes are justifiable—makes it less likely that an individual will willingly initiate or accept such care or support.

Therefore, the extent to which stigma is attendant in considerations of a move to a NH or AL residence is a matter of consequence. If such stigma exists, and if it were possible to influence the attitudes and behavior that lead to stigma in these settings, then older adults and their families might be more agreeable when residential long-term care is indicated.

Simply stated, stigma is a social/psychological response toward individuals who possess characteristics that are devalued in a particular social context and then experience social distance and exclusion (Link & Phelan, 2001). Consequently, the dominant culture—in this case the residential communities in which individuals live—plays a role in determining whether a given individual is stigmatized (Levy, 2003). An individual also may self-stigmatize his or her own condition due to feelings of shame or embarrassment, as well as experience stigmatization during interactions with others—both of which might be setting specific if the condition is not normative in that setting (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Further, in situations when the condition might not be readily identified by others (e.g., incontinence), behaviors to hide the condition might increase the related tension (Crocker, Major, & Steele, 1998). Of note, stigmatization reflects a difference in power that permits negative stereotyping and discrimination and results in groups of "us" and "them" (Link & Phelan, 2001). In long-term care settings, the power role has traditionally gone to staff, who may consciously or unconsciously discriminate against residents who are impaired, or defer to residents' families for decisions about care rather than dealing directly with the resident. Whether it is the dominant culture causing the stigmatization, or of the individual's own doing, it is conceivable that the culture of residential communities may be modified to reduce stigma.

Questions relevant to the matter of stigma in long-term care include how long-term care residents define stigmatizing traits in themselves and others; how they act and react to these traits; how these traits influence social dynamics and behaviors; how stigma operates in different settings; and how the quality of the setting and care might be improved by attending to the personal and social dynamics of stigma. This article addresses the latter two questions: how stigma operates and how care might be improved by attending to stigmatizing structures and processes within the setting. It presents qualitative analyses of data derived from interviews with 256 residents, family members, and staff in five settings that included more than one level of care: one that included independent living (IL) and AL; two that included IL, AL, and NH care; and two that provided AL and NH care. The article is based on the Donabedian (1988) framework of health care quality that posits that structures and processes of care result in (stigmatizing) outcomes: structures are the settings in which care is provided (e.g., facilities and equipment), processes refer to how care is provided, and outcomes are the effects of those structures and processes (Donabedian, 2005). This framework has been used

in countless studies, including those conducted in NHs and AL (Castle & Ferguson, 2010; Grabowski, Aschbrenner, Rome, & Bartels, 2010; Zimmerman et al., 2005).

Specifically, this article addresses how structures and processes of care relate to stigma and might be modified. It recognizes stigma as including concepts such as social exclusion, loss of independence, devaluation due to undesirable characteristics, or outright prejudice and discrimination. Because each of the study's settings included more than one level of care, there is an increased likelihood that the participants were aware of, and might have thoughts about, other levels of care. Text that captured respondents' feelings of stigma (e.g., feeling excluded, recognizing differences between themselves and others) were examined in the context of co-occurring structures and processes of care. In this way, this article analyzed data from interviews not to identify the psychological damage caused by stigma, but instead to identify structures and processes of care related to that stigma, with the hypothesis that it would be possible to identify structures and processes that resulted in and/or related to stigma. This article is innovative in applying a well-established conceptual framework to a novel outcome—stigma—not usually examined in this manner.

Design and Methods

Data for this article are drawn from a larger ethnographic study related to stigma in multilevel senior housing, conducted as one of the Collaborative Studies of Long-Term Care. They were obtained between 2007 and 2012 for five multilevel settings in the mid-Atlantic region, chosen to represent diversity in type, size, profit status, location, and resident racial mix, and that were within a 1-hr drive of the field office. Data collection required approximately 9 months within each setting. Of note, the 256 interviews used in these analyses, with individuals who reside in, work in, or are related to individuals who reside in multilevel settings, are a portion of the data that also included interviews with similar respondents in active adult retirement communities (but whose data were not included due to less relevance to the aims of this article).

Respondents were purposefully selected to reflect variation in age, race, health, and gender as they occurred across the various settings; men and minorities (who are less well represented in long-term care) were especially solicited. Also, individuals residing across various floors and buildings of each setting were recruited. In addition, some respondents recommended individuals whom they considered important to interview (such as because of potentially stigmatizing experiences they had had), and if an individual himself or herself asked to be interviewed, that too was done. This organic process is common to qualitative research (Patton, 1990). Individuals who were not cognitively able to be interviewed (based on staff advice or ethnographer judgment) were excluded from the study although their relatives were eligible for participation.

Potential respondents were recruited by the ethnographer in person or over the telephone.

Ethnographic in-depth interviews were conducted in-person and were approximately 1 hr in duration. Although an interview guide began the conversation and generally directed the interview, participants were free to discuss their experiences in their own terms, and their responses prompted follow-up questions (Gubrium & Holstein, 2002; Seidman, 1998). The interview guide did not include the term stigma; instead it included general questions such as (for residents) asking about how people came to live there, what life is like there, what people talk about, whether there are some who people tend to avoid, where people gather/socialize, and whether residents from different buildings interact with each other; and (for staff and families) experiences working or visiting within the setting and observations of social dynamics. Recorded, verbal consent was obtained for all interviews, and Institutional Review Board (IRB) approval was obtained for the conduct of this study.

Each interview was transcribed, reviewed for accuracy, and separately coded by one or two research team members (i.e., duplicate coding was done during the first 2 years of data collection to establish reliability), using codes derived inductively by the research team. Code development was an intensive iterative process, with team members reading initial transcripts and meeting regularly to identify themes and patterns. A total of 43 codes were developed. When coding discrepancies occurred, they were discussed and reconciled among the pair; if they could not be resolved, they were discussed and reconciled with the larger investigative team during twice monthly team meetings. All narrative data were stored on a shared, password-protected network drive accessible only to research staff.

For these analyses, nine codes were determined to be most relevant. One related to structures of care (i.e., physical setting) and one related to processes of care (i.e., home operations/management/rules), and seven related to stigma outcomes (i.e., belong here/not belong here, exclusion/inclusion, generalizing, image management, power, recognizing difference, troubling behavior). Codes not considered in these analyses include, for example, life history/biographical information and relationships with family, as these and other excluded codes were considered to less directly reflect how the setting's structures or processes of care promote or protect against stigma.

Six members of the investigative team (the authors of this article) read all transcript passages in which the structure of care code "physical setting" or the process of care code "home operations/management/rules" co-occurred with any of the seven stigma outcomes. Transcript passages were discussed by the authors during numerous meetings to identify the themes that were operative in terms of the relationship between structures and processes of care and the outcome of stigma. The development of themes was iterative; that is, during discussions, the number of themes, the terms with which to describe them, and the selection of related quotes (i.e., examples illustrating the theme) evolved over time. For each theme, quotes were identified that both promoted and protected against stigma. All authors, including two who were ethnographers in the field, agreed regarding the resulting themes and related quotes.

Results

The five participating settings included one IL/AL community, two IL/AL/NH communities, and two AL/NH communities (see Table 1). A total of 256 respondents participated from these settings. The largest group was residents (*N* = 113, 44% of the sample), who were primarily white (92%), female (76%), and ranged in age from 39 to 101 years (median, 84). Staff represented another 101 respondents (39%), who also were primarily white (58%), female (90%), and 19–69 years of age (median, 46). Finally, 40 family members participated (16% of the sample), who too were primarily white (98%) and female (70%) and ranged in age from 24 to 84 years of age (median, 64).

Figure 1 lists the four themes that emerged from the data, describing the relationship between structures of care and the outcome of stigma, and the five themes describing the relationship between processes of care and stigma; all are worded in the positive valence, indicating the overriding structures and processes that relate to less stigma based on the results in this study. Tables 2 and 3 provide direct quote examples of how these structure and process themes can both promote and protect against potentially stigmatizing behavior and attitudes, respectively. This text describes each theme.

The first listed theme related to structures of care captured the importance of physical space and included two subthemes: reducing environmental press and using social space for engagement. The theory of pressure from the environment has been applied to the field of older adult housing for more than three decades and posits that a reduction in an individual's competence or an increase in environmental pressure has a negative effect (Lawton, 1974). In this study, the simple act of not repairing a threshold leading into a public bathroom in a timely manner (see Table 2, Physical environment, "Promoting Stigma" column) prohibited a resident from using that bathroom—in essence, creating social distance and seclusion that is definitional of stigma because the resident was uncomfortable being too far from a bathroom, and therefore inadvertently excluded from a social space. On the other hand, having a room immediately across from the dining room (Table 2, Physical environment, "Protecting Against Stigma") enabled inclusion. The example illustrating how social spaces can be made into something stigmatizing (second row, first column) is conveyed by the staff member who said "it's easier to just stick them all in the front and leave them there," (referring to staff

situating immobile residents near where the staff themselves are stationed for their own ease) in contrast to residents and family members who perceived spaces as opportunities to promote engagement (e.g., "everyone who wants to attend has the chance whether they are in a wheelchair or can come in by themselves or have other family members meet them there").

Another theme related to structures of care included three subthemes, all of which reflect the case mix (i.e., types) of the residents: assuring commonalities, recognizing death, and avoiding labels. Social engagement is more likely among individuals with similar backgrounds and interests (McPherson, Smith-Lovin, & Cook, 2001), and other work has shown that characteristics of a residential setting relate to residents' participation in activities (Zimmerman et al., 2003). In this study, commonalities among residents both promoted stigma by enabling cliques (Table 2, "birds of a feather flock together") and protected against stigma ("with all church people you share certain common standards"). Case mix extends to those at the end of life, and most AL regulations prohibit admission or retention of residents who require ongoing skilled nursing or other care not within the setting's licensed authority (Polzer, 2013). That said, many residents die in AL and NHs (Munn et al., 2007). One resident resented that the staff withheld information about a resident's death or hospitalization; he felt that the staff was "overplaying" HIPAA (Health Insurance Portability and Accountability Act) regulations by making it impossible to know the whereabouts of his friends. In this example, stigma is operational because the resident was treated as an "outsider"; if he were living in a private

home, he would merely ask the family members about his friend who died. On the other hand, an openness regarding death and dying that does *not* shroud these natural events in a veil of secrecy, or treat AL residents as "outsiders" unworthy of knowing about the death of another resident to whom they are close, does not stigmatize the death. The final subtheme related to case mix was the obvious use of labels to describe different types of residents, of which there was no paucity such as "Hoyer" (the brand name of an assistive sling to transfer people between a bed, chair, or other resting place), "feeder," and "pauper," which in and of themselves promote recognized differences and are demeaning and depersonalizing. On the other hand, an administrative staff member expressly noted that staff "are not supposed to refer to people based on their condition … and I say to them 'would you want someone to refer to you like that?'" Staff sensitivity to labels is an important consideration in terms of protecting against potentially stigmatizing attitudes and care.

Similarly, training staff to provide appropriate care was identified as a theme that can protect against stigma, such as by creating a sense of security to express a need for care. The opposite experience, illustrated by staff poorly trained to help transfer a resident who then blamed the resident herself for the staff's elated injuries, resulted in the resident feeling insulted and embarrassed.

Finally, most examples regarding how structures of care potentially promote stigma reflected the very nature of multilevel settings. Evidence from other work suggests that residents in continuing care retirement communities (which include IL, AL, and NHs) perceive transitions as

Table 1. Settings (*N* = 5)[a] and Respondents (*N* = 256)

Setting type	Number of settings	Size	Respondents
IL/AL	1	IL, 60 units; AL, 137 beds	*N* = 46 (resident, 22; family, 8; staff, 16)
IL/AL/NH	2	IL, 30 units; AL, 110 beds; NH, 88 beds	*N* = 36 (resident, 19; family, 7; staff, 10)
		IL, 199 units; AL, 60 beds; NH, 162 beds	*N* = 94 (resident, 43; family, 10; staff, 41)
AL/NH	2	AL, 78 beds; NH, 22 beds	*N* = 31 (resident, 13; family, 6; staff, 12)
		AL, 93 beds; NH, 62 beds	*N* = 49 (resident, 16; family, 10; staff, 23)

Notes: AL = assisted living; IL = independent living; NH = nursing home.
[a]Two settings were not-for-profit (one IL/AL/NH and one AL/NH) and two had a dementia care unit (one not-for-profit IL/AL/NH and one IL/AL).

Four Structures of Care
Physical environment: Reducing environmental press; using social space for engagement
Case mix: Assuring commonalities; recognizing death; avoiding labels
Staff training: Providing appropriate care
Multi-level settings: Minimizing "us" versus "them"
Five Processes of Care
Dining: Creating a positive experience
Independence: Supporting autonomy
Respect: Valuing the resident
Privacy: Providing privacy
Care provision: Taking the focus off of decline

Figure 1. Structures, processes, and related themes to reduce stigma.

Table 2. Structures of Care: Themes Promoting or Protecting Against Stigma and Exemplar Quotes

Theme	Promoting stigma	Protecting against stigma
Physical environment		
Reducing environmental press	Staff (referring to repairing a threshold to the bathroom): *We can't do it because it's not within the [budget], it will be coming up the following year.*	Family: *He's very happy with the room he has. It's right across from the dining room so he doesn't have to go far for that, like today when he's not feeling well, he doesn't have to walk a great distance.*
Using social space for engagement	Staff: *But then this is what I think, okay, what are they going to do? Put them in a room with nothing to do? They can't! And no supervision? So, they can't. So it's easier to just stick them all in the front and leave them there.*	Resident: *We can sit and - like we sit in the dining room and talk after dinner and laugh at things and it's hard. It's all kind of different classes or nationalities of people and we're all trying to get together and I think it's pretty good.* Family: *You know, Bingo is definitely a more inclusive kind of setting because … they even delay administering medication until after Bingo. So that's a big event. And chapel service is very inclusive, you know, everybody who wants to attend has the chance whether they are in a wheelchair or can come in by themselves or have other family members meet them there.*
Case mix		
Assuring commonalities	Resident (referring to feeling judged by more conservative residents): *Well, I think it's like that, birds of a feather flock together.*	Resident (referring to acceptance of non-church members into the setting): *With all church people you share certain common standards.*
Recognizing death	Resident (referring to how death is communicated to residents): *It's not. …and HIPAA, I mean you just fall into the black hole of Calcutta, which I think is not right. … I don't know why they overplay that [HIPAA]. And I think that does something about this feeling of closeness, so it becomes more of an indifference attitude.*	Family: *They don't pretend, you know, they accept that and it's a very open thing … So yeah and I think that's a good thing, absolutely. … it's not a secret, and it's not a horrible thing, it's part of what goes on there.* Resident: *A tenant became very ill here and somehow or other they knew that she was dying and she was elderly, very elderly, and she made it known - I think she guessed that she was dying and she wanted to die in her room. And she was allowed to stay in her bed … The family had their memorial service right down in the parlor where the puzzle is, but it was just for the family.* Interviewer: *Were the other residents given the opportunity to go in and visit and say goodbye?* Resident: *Yes when she was in her room and ailing.*
Avoiding labels	Resident, who had visited the setting as a volunteer before now becoming a resident: *But it was kind of strange when I moved in; the Visiting Committee [was] having a meeting and I went into them, I said, "Hey I want to come [to volunteer]; can I come too?" They said, "No, no, you're a resident now. You can't come visit."* Staff: *We try to sit the feeders as close as possible so that we can sit there and feed two at a time or whatever that we need to do.* Staff: *It used to be looked at, they were paupers. I'm occasionally still seeing that image.*	Staff (referring to labels such as "Hoyers" or "feeders"): *They [staff] are not supposed to refer to people based on their condition … and I say to them "would you want someone to refer to you like that?"*

Table 2. Continued

Theme	Promoting stigma	Protecting against stigma
Staff training		
Providing appropriate care	Resident: *Before the Hoyer lift, two girls, individually at different times, their backs were injured because they improperly took me from the bed to the chair … [one of the girls] was improperly insulting me … I felt embarrassed.*	Resident: *You tell your nurse and your social worker and they'll handle it. I feel comfortable … you're not out in left field by yourself. You have people you can turn to about issues being met … you're safe. You're not ignored; you're not ignored at all.*
Multilevel settings		
Minimizing "us" versus "them"	Staff: *That's one of our hardest things here is actually moving one resident from one level of care to the other … it's traumatic for them and it's traumatic for us. The hardest is usually from the apartments to a different level of care. Sometimes it's just you know their stereotype idea of what it's like to be going from the apartments to [skilled care]. That's where people go to die, that's where people go that don't know what they're talking about, that's where people go who all they do is you know sit there and drool. So it's hard to get over that.* Staff: *The third floor is taboo. I don't know the word for it, but it's like you say "third floor" and they're like—"oh no, I won't .. don't want to go up [there]."* Staff: *It's like in management, it's "us and them." … we say when they're going—coming over to the assisted side, it's over to the Dark Side (laughs) just like Star Wars.*	Staff: *Right, so then they started you know saying, "Oh, it's not so bad"—the assisted living residents and then they start coming over here and we have independent living residents that come visit assisted living residents and especially some of the assisted living residents that lived in Independent. So they come over here faithfully.* Staff: *We're trying to … make it a more attractive place …to remodel upstairs to make it a destination room … so they can … see that the third floor is not a bad place. It's just people are needier up there.*

disempowering and similar to those that occur across levels that are not part of the same setting, yet research in this area is limited (Shippee, 2009). The few examples provided in Table 2 are illustrative of the many heard in this study, which basically reflected perceptions of "us" versus "them" that arose when more than one level of care is present on the same campus. Staff noted that the move is "traumatic," attendant with stereotypes of more intensive levels of care housing people who are dying, don't know what they're talking about, and sit and drool; additional phrases used were "taboo" and "going over to the dark side" (Hrybyk et al., 2012). Efforts to protect against stigma were less common; they included promoting frequent contact between residents who reside on different levels and remodeling to make the more intensive level of care more of a "destination" for shared activities or services such as the beauty shop.

One of the five processes of care related to stigma reflected the importance of creating a positive experience during dining. The significance of food and dining in long-term care is legendary, with reports noting the importance of autonomy related to food choice (Kane et al., 1997) and of food enjoyment and dining with others to improve quality of life (Burack, Weiner, Reinhardt, & Annunziato, 2012; Carrier, West, & Ouellet, 2009; Frankowski, Roth, Eckert & Harris-Wallace, 2011). In this study, stigma was promoted by a policy that excluded residents' wheelchairs from the dining room and by a practice that allowed some residents (the self-named Prima Donnas, with the name changed here to protect confidentiality) to side-step waiting in line to enter the dining room (see Table 3). Processes to protect against stigma included supporting a resident-initiated "discussion group" to address the reserved dining table for the Prima Donnas, an informal practice that made other residents feel "like they're an outcast"; attempts to sit residents together who get along well to promote inclusion; and encouraging residents to socialize over meals while also inviting new residents to join them.

Another process of care related to stigma is independence, most notably supporting residents' autonomy. The importance of autonomy is well established in areas as far ranging as preferences for medication administration and

Table 3. Processes of Care: Themes Promoting or Protecting Against Stigma and Exemplar Quotes

Theme	Promoting stigma	Protecting against stigma
Dining		
Creating a positive experience	Staff: *I guess the rule of the house was that wheelchairs were not allowed in the dining room. [Resident 1] has to get out of her chair and come in, she has multiple leg problems and now [Resident 2], or whatever his name is, has come in with a big wheelchair, so big that he has to go around and come in through the hall. And there is some talk about that; they're not happy with it. If he can come in [with his wheelchair] why can't other people come in [with theirs]?* Staff #1: *I'm sure you've seen we've got our little table in the back, the Prima Donna table. And believe me, if you're not one—at dinner time you don't go to that table. There have been problems in there. I mean because people will go that don't realize what is—I mean especially newer people, that don't realize it and I think there have been some hurt feelings from people that have been removed from the table. I think the table is not fair. I mean if they all want to go to that table that's fine, but to have that sign on the table and to actually remove people from the table, I think is inappropriate …. what makes them any better than anybody else that they can go in any time they want. They don't have to wait in line; they just get to the table and what does that tell my other residents. Are they better than them? No, no better.*	Staff: *Usually the tables are already set most of the time and if I put somebody at one table and if they don't get along then of course we arrange the table— we place somebody somewhere else.* Staff: *You know this Prima Donna group upstairs, will be the death of me yet because they're like a high school clique and they drive me crazy. They're one of the biggest reasons we started [a discussion group]. So if you think that old people don't have cliques, and aren't judgmental, we're all wrong about that because they can be really judgmental and very cliquey, and they make other residents feel like they're an outcast. So sometimes that's a significant issue, too … we walk a fine line because we have to protect all the residents' rights, and yet we still have to have life happen, so it's pretty interesting about where you get involved and where you don't.* Staff: *A lot of them [residents] have established friendships from coming down for lunch or for dinner. And I've noticed, you know, one group of ladies, they sit together and they don't want you to switch them up, they don't want a new person there at the table because they're all friends and they've established that friendship. So that's a good way to help them to socialize. Especially when you get the new residents and then you put them at the table, and then they sort of develop and you can see that friendship blossom from that point.*
Independence		
Supporting autonomy	Resident: *I cleaned it up. So that was my kind of volunteer job, over a year I did that … we were getting ready for Bingo… and they didn't want to clean up the dining room. So I started cleaning it up. And [staff] said, 'What are you doing? … You can't do that.'* Interviewer: *Now why was that?* Resident: *Because I'm a resident, not staff—it's not my job. But it's my HOME. If I was home, I would do the same thing at home.*	Resident (responding to the very best thing about living there): *it's the freedom I have. I was surprised that somebody said go talk to [administrator] when I mentioned that I would like to do such and such. And I went and talked to her and I said "May I every once in a while catch the bus and go into town to go to mass and to do a little shopping?" "Sure."* Interviewer: *Did you think moving in here that, that would not be an option for you?* Resident: *No I didn't know that that would be an option for me. I would have just been more willing to come here, I think, if I had known that. I would not want to be in a place that keeps watch over me.*

Table 3. Continued

Theme	Promoting stigma	Protecting against stigma
Respect		
Valuing the resident	Resident: *At first I felt like a prisoner because you couldn't do this, you couldn't do that. Don't do this and don't do that and—oh you couldn't do that, and you better not let them see you do that. I was scared all the time at first that I was going to do something and everybody would jump all over me… And at one of the town meetings somebody got up and asked something about something and they said no … well it makes you feel like you're a prisoner. Like you're a number not a person.* Resident (who was cognitively oriented and felt staff were stealing from her): *They are afraid of firing people because they said that nobody wants to work here, that it's too much work and little money. But then I told them [that a staff member stole from me] and they didn't believe me; they believed her.* Resident: *I asked why our laundry room has these horrible old washing machines and dryers. They've certainly outlived what they cost. Why can't they—instead of when one breaks like it does, instead of them patching it up [why not replace it?] The floor needs re-doing. It needs painting desperately; it's very depressing to go there.* Staff (talking about the agenda for a resident council meeting) *My agenda for it is … very benign. We're talking about all the new residents, the pharmacy change, the food committee report, the guest room donation fees to have a guest stay overnight, the carpet issue, some new activities we're doing and not doing to turning on the air conditioning in the public rooms … it's very benign.*	Interviewer: *The [motto] is do unto others …* Staff: *Others as you would have them do unto you, uh-huh … We start even with our orientation … it has to be a way of life, you can't just, you know, you're not just doing that to the residents, you're not just doing that to their families, you're doing it to your coworkers because they see and they hear, um, and they can be laying in the bed and hear you, you know, backtalk your coworker and then you come in and be nice to them, they hear and that stuff registers.* Staff (talking about a family member): *"If you want to leave, I can't stop you." I said, "But we are going back upstairs and you're going to tell your mother that you're leaving." I said, "You're not going to leave that to me or any of us … You're going to be the one to tell her that. And I'm not going to be put in the position of making excuses for why you didn't even tell her you were leaving." It wasn't going to set up very much trust for us to take care of her if I was part of a lie with her daughter, in conniving.* Staff: *Over here [nursing home] we have more people with the Hoyer and because they're Hoyers they can't be on assisted living, but there's not much difference in how you feel about them or care for them.*
Privacy		
Providing privacy	Staff: *If the behavior (sexual) was in his room, if it was with another consenting adult I would have no problem, I mean you know what—go in and shut your door and do what you got to do, and so be it. I mean we're all human, but hallways, out in the open I just—I do have a difficult time dealing with it and I guess especially because everybody is aware of it and nothing is being done.* Resident (referring to taking medications): *They allow me to—they figure I'm still okay up here to pick the right pill whereas—they're probably gathering now because it's almost 12:30, but that's where they—those that can't, they dispense them.*	Resident (responding to a question about whether staff talk about other residents): *Well, sometimes … and of course we're not allowed to know anything. On the other hand we say we're all one happy family, we're all supposed to be family you know. But they don't tell us that—evidently that's a government regulation.*
Care provision		
Taking the focus off of decline	Staff: *I try not to be in the room [at mealtimes] because the moment I'm in the room then the focus is on this white uniform, and on me, and if they had a problem now, they're going to think about it, but what I do is stand outside and I can see through the reflection of the … glass door. You've got to learn the tricks and the way that they have the door at an angle,*	Staff: *You're not allowed to stand over a resident and feed them … because they feel like you are towering over them … hovering over them, they feel like you are superior to them. I wouldn't like somebody standing over me with a fork.*

Table 3. Continued

Theme	Promoting stigma	Protecting against stigma
	I can see almost everybody in that room and listen to what's going on. So I check a few times while they're eating, see them physically, see them starting to get up and go but always disappear quickly, that way they don't know they're being watched. Are they forgetting eight times in a row … okay, let's watch. And the housekeeping staff watches them, housekeepers are great. They see the first problems of the hoarding and the incontinence and every other issue that we have. Resident: *This is supposed to be a place where you can take care of yourself…. That's what they tell you when you come in. So you're going to be very reluctant to complain-and this is not just my thought. This is what these people say.*	Staff: *[Resident] was about the only resident that I can recall that was into hiding, trying to hide certain things and that's because she [Administrator] didn't want anyone to say, "Well you've reached a certain point and we can't keep you." [Administrator] has reiterated to the staff not to say certain things.*

the ability to lock one's own door; a lack of autonomy can result in feelings of depression (Carder, Zimmerman, & Schumacher, 2009; Chen, Zimmerman, Sloane, & Barrick, 2007; Morgan, 2009). In this study, stigma was engendered when a resident tried to help clean and prepare a room to play Bingo but was curtailed by the staff who reminded her she was a resident, not a staff member; she continued to state that if she were at home, she'd be doing the cleaning and preparation. A quite different example, which protected against stigma, was the resident who reported the very best thing about living there being "the freedom I have", and "I would have been more willing to come here, I think, if I had known that. I would not want to be in a place that keeps watch over me."

The next process of care—valuing the resident—includes an example that is an extension of the concept of autonomy. The first example illustrating the promotion of stigma is from a resident who said she felt like a "prisoner" due to a lack of autonomy, concluding that she feels like a "number, not a person." This devaluation is definitional of stigma (Crocker, Major, & Steele, 1998). Additional examples of the stigma that results from lack of respect were voiced by a resident who reported that staff did not believe her report that a staff member had stolen from her, and another who reported the depressing practice of "patching up" appliances that were "horrible" and "outlived what they cost" rather than replacing them (suggesting that the residents did not merit new appliances). A rather telling example of devaluing the importance of the residents was provided by an administrative staff member, who expressed that the agenda for the resident council meeting—which included introducing new residents, a pharmacy change, the food committee report, fees to have guests say overnight, an issue with the carpeting, new activities, and not turning on the air conditioning in the public area—was "very benign," and in fact making that point not only once, but twice. Merriam Webster defines "benign" as "having no

significant effect," and to consider an agenda as substantive as this to be benign, which included many items of likely importance to the residents (e.g., additional fees, discomfort due to the temperature), typifies devaluation. Examples that protected against potential stigma by expressly valuing the resident included an administrator who noted that beginning with staff orientation they stress the "golden rule" of "do unto others as you would have done unto you"; another staff member who refused to be part of a resident's daughter's lie, noting that doing so would disrupt the trust she was establishing; and yet another who noted there being "not much difference in how you feel about or care for residents" who are in a NH versus AL.

Processes related to privacy also were seen to promote or protect against stigma. On the negative side, a resident's sexual expression was stigmatized by staff who noted that although such behavior is "human," it was being expressed in the hallways and nothing was being done about it. Another example was expressed by a resident who differentiated herself from others who were less competent because she was "still okay to pick the right pill" without help, in the privacy of her room, whereas staff were "probably gathering right now … (for) those that can't." The variable activity of medication management, as evidenced through privacy or the lack thereof, created a situation of "us" versus "them" (Link & Phelan, 2001). In another example, privacy-related stigma was protected against by a resident who implicitly referred to HIPAA regulations when noting that staff do not talk about other residents.

The final process of care example identified in this study related to care provision, most notably taking the focus off of decline. One staff member, who was sensitive to the likelihood that his white uniform would make residents think about their problems, instead used "tricks" (stand outside and watch through the reflection of the glass door) to watch and listen to the residents, and "always disappear[ed] quickly" so they would not "know they're being watched,"

also noting other strategies to identify "every other issue that we have." Care strategies such as these very much illustrate the power differential that permits negative stereotyping and discrimination and allow for an "us" versus "them" differentiation (Link & Phelan, 2001). Taken one step further, fear of being moved led to the tendency of declining residents to hide conditions (Crocker, Major, & Steele, 1998), one of whom noted that because "this is supposed to be a place where you can take care of yourself … you're going to be very reluctant to complain." On the other hand, stigma was protected against by care practices prohibiting standing over residents while feeding them so as to not convey a feeling of superiority, and administrative practices to expressly not tell residents things such as "well you've reached a certain point and we can't keep you."

Discussion

Before putting the findings of this study into a broader context, it is vital to make four points. First, the concept of what is considered stigma is variable, and some of the examples described herein—while illustrating social distancing or devaluation by others—might not be universally considered as "stigma." Second, some of the stigma that the respondents discussed, for example, related to reactions to decline, is societal stigma and by no means exclusive to the province of long-term care settings (Dobbs et al., 2008). Third, in *no* instance was there any indication that structures or processes of care were in place intentionally to promote stigma—although some *were* expressly in place to protect against stigma (such as the two examples noted immediately above). Consequently, administrative and other staff are generally sensitive to the stigma that can be engendered in AL and NHs through their structures and processes, and when aware, take steps to prevent it. The findings indicate, however, that there are numerous instances when staff may not be aware of the stigma-inducing components of their organization and/or may not have identified steps to avoid them. A fourth point important to note at the outset is that this article's analysis identified structures and processes of care that related to the outcome of stigma. It cannot be said that any one "setting" in and of itself is stigmatizing, in large part, because (as shown) a given structure or process can both promote and protect against stigma; settings typically have both favorable and unfavorable structures and processes; and individuals' reactions to the structures and processes may differ (Hrybyk et al., 2012; Sandhu, Kemp, Ball, Burgess, & Perkins, 2013; Zimmerman, Sloane, & Fletcher, 2008). However, it *can* be hypothesized from our findings that stigma may result given specific manifestations of structures and processes of care. In this regard, the Donabedian (2005) model of structures, processes, and outcomes elucidated important relationships.

One especially thorny issue is the matter that some structures and processes may both promote and protect against stigma; the matter of HIPAA is one such example.

Although HIPAA established national standards to protect certain health information (United States Department of Health & Human Services, 2003), it also has been noted to do more harm than good when it impedes communication between health care providers (such as when a resident is cognitively impaired and the decision maker is not available; Kaidy, 2004). This study illustrates that HIPAA also has implications for the outcome of stigma. On the one hand, the enforcement of HIPAA to not discuss residents' death or hospitalization created social distance among fellow residents (a bad outcome), at the same time it promoted privacy (a good outcome). Awareness of this dichotomy might encourage practices to expressly ask residents and document their permission to share certain information under certain circumstances with specified individuals, a strategy one setting was beginning to employ toward the end of data collection.

Another thorny issue is the matter that some of the stigma-promoting structures and processes of care are not entirely of the organization's making and instead reflect stigma that residents themselves harbor. The themes of case mix (a structure) and dining practices (a structure) provide one such example, as both illustrate the cliques that form naturally among like individuals. Although practices might be put into place to limit the resulting stigma—and indeed were put into place by one organization's institution of a discussion group—it is challenging and not realistic to expect that societal stigma stops at the front door of an AL residence or NH. One strategy that might be put into place to reduce cliques during dining is borrowed from that used successfully in college classrooms—the use of personalized name tents to randomly assign seating as a standard practice, which increased social interaction and reduced isolation (Levey, 2010). Although an organization might not use such tents every day (which could interfere with resident autonomy), a resident council might be asked to consider, endorse, and promote their use on a regular, but not daily, basis, so as to not interfere with the development of natural bonds. Another practice that has been used is to seat residents in the order in which they arrive to the dining room, allowing those who want to be seated together to arrive together and also assuring that no one is excluded from being seated in a certain location.

Perhaps the most straightforward situation is when a structure or process is uniformly considered to be stigma inducing, as was the case of perceptions of being surreptitiously "watched" by staff to monitor either for activities that are prohibited or for decline that suggests the need for more care. Unfortunately, this situation is akin to a double-edged sword, in that it is desirable for staff to monitor resident change to promote optimal care, yet uncomfortable for residents to perceive they are being watched. Sensor technology has made it possible to unobtrusively monitor activity, time spent in bed, heart rate, respirations, pulse, and other functions (Rantz et al., 2013). However, some individuals may find such technology to violate personal

privacy and be stigmatizing in its own right; consequently, it is recommended that monitoring be done only of conditions that are of concern to the resident and with their consent (Demeris et al., 2004). Similarly, monitoring of conditions without the use of such technology also should be done only with the resident's awareness and consent.

Another structure of care that almost universally elicited reactions of stigma was the very nature of multilevel organizations. Of all structures and processes identified in this study that elicited stigma, this one may be the most momentous because the related stigma expressly influences an individual's desire to accept needed care. Whether individuals are drawn to a multilevel setting because it allows for transitional care without moving to a new campus, or in response to the less intense level of care (without giving thought to the other levels), the reality is that transitions within multilevel settings are more challenging than most anticipate (Eckert, Carder, Morgan, Frankowski, & Roth, 2009). Also, and virtually unknown to most individuals, is that transfer to a more intense level of care is actually more likely if one resides in a multilevel setting (Zimmerman et al., 2005). Prior research suggests that such moves are stigmatizing for reasons related to both the individual and the setting. On an individual level, the primary matter is that it confronts individuals with the reality of their own decline, threatens their prior sense of self, results in dismay about the future, creates barriers between them and those who remain more able, and awakens their recognition of the stigmatized nature of their new identity (Shippee, 2009). One might surmise that these reactions are heightened when the transition occurs in a multilevel setting because reminders of the prior self are quite literally right next door.

The other setting-related reasons that make transfer to another level of care stigmatizing are potentially more malleable. They include lack of decisional control over the move (i.e., it is often an administrative decision, arrived at after having observed decline); subsequent loss of privacy and space; reduced freedom resulting from practices such as restricted dining hours or ability to maintain control over medications; and the fact that rules related to having to make a transition are ambiguous and less consistently applied to those of higher status (Iwasiw, Goldenberg, MacMaster, McCutcheon, & Bol, 1996; Reinardy, 1995; Shippee, 2009). Recommendations to reduce the related stigma include using marketing materials and workshops to clarify the situations under which transitions occur; assigning a resident and/or staff liaison to promote continued socialization with family and friends and across levels of care; providing activities expressly intended for residents from all levels; structuring committees that include residents from all levels; facilitating visits outside of the building; and providing more personal space if such is lacking in the higher level of care (Iwasiw et al., 1996; Shippee, 2009). Some of the settings in this study intentionally promoted social interaction across levels and were remodeling space

to create a "destination room," indicating that such changes to processes and structures of care are feasible although not without their challenges (Doyle & Rubinstein, 2013).

Other suggestions to reduce stigma in AL and NHs derived from this study include attending to the physical environment to reduce environment press and support social engagement; training staff to avoid using labels and provide care appropriate to resident needs; promoting independence (such as by supporting autonomy if a resident chooses to clean a public space); and conveying respect (through actions that value the residents such as believing their concerns). Although none of these concepts are likely to be unfamiliar to owners, administrators, and providers, what likely is unfamiliar is that lack of attention to these areas can result in stigma. Surely no senior housing settings are intentionally designed to stigmatize others, and fortunately, there is now evidence to suggest that while unintentional, the way these settings provide care and are designed can be modified to reduce stigma in AL and NHs. Next steps and the related research agenda include examining this topic in more diverse settings, implementing revised structures and processes, and determining the extent to which resulting stigma can be reduced or avoided.

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